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HOSPICE SOCIAL WORKERS' ATTITUDE ON PHYSICIAN-ASSISTED
SUICIDE AND PRACTICE UNDER CALIFORNIA'S END OF LIFE OPTION ACT

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Veronica Lorraine Fausto Melchor

June 2018

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ABSTRACT

Currently in the United States, five states have enacted physician-assisted suicide as a legal end of life option for terminal patients. Research indicates that most patients who have died under this mean have been enrolled in hospice services. With the recent enactment of California's End of Life Option Act, hospice social workers will find themselves educating and assisting patients and/or their families with this and other end of life decisions. Research has thoroughly examined physician and nurses' involvement and attitude in the matter, but little has been researched regarding social workers. This study aimed to identify the factors that affect hospice social workers' attitude towards physician-assisted suicide and how California's End of Life Option Act affects their practice. In-depth face-to-face interviews with 8 hospice social workers were conducted. The study found that all 8 participants held positive attitudes towards physician-assisted suicide, support the End of Life Option Act, and feel prepared to assist patients and handle requests for the End of Life Option. Factors such as social work values and professional experience have a positive effect and validate their attitude, and factors such as religion does not affect their attitude. Due to low participation, the overall results were limited; therefore, additionally research should be extensively conducted to gain a better understanding. Regardless, a structured physician-assisted suicide protocol for social workers would benefit micro practice and macro developments.

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CHAPTER ONE

ASSESSMENT

Introduction

Chapter one covers the study's research focus, which regards to physician-assisted suicide and social workers' attitudes towards it and the effect of California's End of Life Option Act on social work practice. It identifies the paradigm of the study and provides the rational for this perspective. This section provides an overview of physician-assisted suicide and its history and presents society's overall attitude towards it. Additionally, the literature review focuses on what past studies indicate regarding physician-assisted suicide's effect on social workers' practice and their attitude towards it. It also presents various factors that affect social work practice and attitude. The study's theoretical orientation is explained as well as its contribution to micro and macro social work practice.

Research Focus

The research focus of this study was an identification of factors affecting hospice social workers' attitude towards physician-suicide and the effect of California's End of Life Options Act on social work practice. Data was attained from relevant studies and studies based on Oregon and Washington's practice of physician-assisted suicide under their Death with Dignity Act (Oregon Revised, 1994; RCW 70.245, 2008).

To understand the physician-assisted suicide acts enacted in states like

Oregon, Washington, and California, it was important to understand the overall concept. Essentially, physician-assisted suicide involves a physician deliberately helping a terminally ill patient die by informing them how to commit death by educating on lethal doses and/or prescribing a life-ending medication (World Medical Association, 2015). One must note that physician-assisted suicide is not euthanasia. Also, it was important to note that physician-assisted suicide is interchangeably referred to as physician aid-in-dying, death with dignity, and hastened death, among various other names. However, equally important, is to note that the term physician-assisted dying or terms that do not connote suicide are preferred, but this paper uses the term physician-assisted suicide due to originality and common recognition.

Euthanasia is a process that requires a physician to administer a lethal dose of medication to a patient with the goal of ending their life due to pain and suffering (Guy & Stern, 2006). In the United States, this practice is illegal due to its controversial nature and ethical conflict of having a physician directly administer the fatal dose.

There have been occasions where terminally ill people have taken it upon themselves to die on their own terms by committing suicide. It has been argued that in the context of terminal illness, suicide holds a different meaning since at that point the action may be rational due to the prognosis (Marzuk, 1994). Due to the uncertain definition, doctors have unintentionally and sometimes intentionally reported the death as natural instead of a suicide, making it difficult to track the

exact number of suicidal occurrences (Marzuk, 1994). Regardless of the rationale, suicide, in general, is not an acceptable practice.

Improved medical care has led to people living longer now than in the past (Gellie, Mills, Levinson, Stephenson, & Flynn, 2014). Consequently, well managed terminal illnesses have resulted in an extended dying process. People have lived longer with terminal illness due to technological and medicinal advances, however, this does not indicate that a person's quality of life was maintained (Poor & Poirrier, 2001). Those with a terminal disease may have experienced intolerable pain and suffered emotionally, psychologically, and physically during their course of end of life. Regardless of such advances, for some people the fear of dying and concerns regarding quality of life remain (Gellie et al., 2014).

Throughout the years, it became evident that some people living with a terminal illness had the desire to end their life on their own terms. Thus, the concept of physician-assisted suicide developed. In this process, the physician does not directly kill the patient but instructs him or her how to do it himself or herself. This way patients are responsible for taking their own life through life-ending medication, but it remains controversial. Physician-assisted suicide remains illegal in most states but may be considered more acceptable than the latter practices.

It was understood that social workers assist people with end of life planning and decision making. Therefore, it is important for social workers to

keep up to date with developing policies and measures that affect their practice. The recently enacted physician-assisted suicide law in California may change how social workers' assist and handle end of life situations with terminally ill patients. Being that it is a sensitive topic relevant to suicide, and social work aims to intervene and prevent suicide and self-harm, it was interesting to explore how social work practice would be affected under legal physician-assisted suicide. Even though it is different from traditional suicide, it still involves people ending their own life, thus, it poses ethical challenges within the social work discipline.

Paradigm and Rationale for Chosen Paradigm

This study was completed using the post positivist perspective because of its objective approach and use of qualitative data. This paradigm aided in developing an understanding of the effect of physician-assisted suicide on social work practice and the factors that affect social workers' attitude. Such understanding was gained by conducting interviews with Californian hospice social workers', whose practice is relevant to the field of death and dying. Hospice is a natural setting relevant to physician-assisted suicide.

Interviewing these social workers gave the researcher the opportunity to attain meaningful explanations unlike the limited and/or scaled responses that could be given through surveys. As stated by Emanuel (2002), physician-assisted suicide has been studied mainly using general surveys, only a few studies have conducted a comprehensive analysis. Therefore, qualitative data functioned best for this study since it gave a deeper understanding of what

factors affect thought processes and the conclusions the participants came to.

By interviewing these social workers and examining relevant research and studies, based on Oregon and Washington's practice in physician-assisted suicide, one discovered how this practice affects social work in the death and dying field. This qualitative data was analyzed to develop an identification of what factors affect social workers' attitude and practice, which may identify their sense of preparedness to practice physician-assisted suicide under the End of Life Option Act. Considering how new this law is, collecting qualitative data straight from the source gave one a better understanding and an opportunity to identify how social workers are impacted here in California. Collected data shed light on what aspects of social work practice, regarding physician-assisted suicide, administrators and policies makers need to focus on.

Literature Review

This study's literature review presented a background of physician-assisted suicide laws and gave specific details about California's End of Life Option Act. It also presented the statistics of use of physician-assisted suicide in Oregon and Washington. Additionally, this section discussed society's general attitude towards physician-assisted suicide, as well as social workers' attitude, sense of preparedness, and their practice under this law, and the factors affecting social workers under physician-assisted suicide.

Background

A total of five states have legalized physician-assisted suicide. The first

state to enact this practice was Oregon, in 1997, but its law was revised in 2004, second was Washington in 2008, and last was California in 2016 (Oregon Revised, 1994; RCW 70.245, 2008; Assem. Bill 15, 2015; Death with Dignity Act, n.d). True to the nature of physician-assisted suicide, the law in these states allows terminally ill patients to receive prescribed lethal medication, from a physician, which they are required to self-administer. States that legalized physician-assisted suicide have mirrored the basic requirements that Oregon first introduced- the patient must be at least 18 years of age, a resident of the state, be terminally ill with less than six months to live, be cognitively capable to make voluntary decisions, and needs to make two verbal and a written request for physician assisted suicide (State-by-state, 2015).

California's End of Life Option Act

Because this study aimed to develop an identification of what effects Californian hospice social workers' attitude and how their practice is affected by the recently legalized use of physician-assisted suicide, specifics about this state's law are presented.

California's End of Life Option Act requires that the requesting person must be at least 18 years of age, be a California resident, must have a terminal illness and diagnosed by their primary care physician, and have less than six months to live, have the mental capacity to make their own medical decision, make the request themselves free from pressure from others, make the request twice at least 15 days apart, then submit to their primary physician a written

request and have two witnesses for it, and be able to take the lethal medication on their own, and the person should have been informed of other and all end-of-life decisions (Assem. Bill 15, 2015).

It was important to note that it is required for the physician be licensed in California and to certify that the patient is competent and capable of making their own decisions. Also, physicians hold the right to decide whether they will or will not participate in the End of Life Option Act (Assem. Bill 15, 2015). They are not mandated or obligated by law to cooperate in physician-assisted suicide under the act.

Statistics of Use

Data regarding the use of physician-assisted suicide was attained from Oregon and Washington' practices since these states have legally been practicing physician-assisted suicide the longest of all other legalizing states.

The 2015 annual report of Oregon's Death with Dignity Act demonstrated that in the 17 years of its existence, there was 1,545 prescriptions written for death aiding medication yet only 991 patients administered the fatal dose (Oregon's death with dignity,2015). The number of prescriptions written each year increased. In 1998, only 24 prescriptions were written yet in 2015 a total of 218 prescriptions were written. In 2015, 132 patients died by physician-assisted suicide. The number of deaths by physician-assisted suicide increased throughout the years, increasing by 24.4% in 2014 and 2015 (Oregon's death with dignity,2015). Patient characteristics maintained consistent. In 2015, most

were over the age of 65, married, white, well-educated, diagnosed with cancer, and were under hospice care (Oregon's death with dignity, 2015). Gender rates were close to even, with the total of males at 51.4% and females at 48.6%.

Considering the 11-year difference, a larger rate of people participated in Washington's Death with Dignity Act than in Oregon. From 2009 to 2015, 938 terminally ill patients participated and 917 died administering the fatal dose (Washington State Department, 2016). The death trend increased from 65 participants in 2009 to 213 participants in 2015. Like Oregon, rates were close to even between males and females, and most participants were white, married, over the age of 65, well-educated, were diagnosed with cancer, and were under hospice care (Washington State Department, 2016).

Society's General Attitude

Research indicated that, collectively, about 65% of the American population supports physician-assisted suicide; however, its attitude is based on a "rule of thirds" (Emanuel, 2002). It was concluded that about a third of society accepts physician-assisted suicide regardless of the terminally ill person's situation. Emanuel (2002) informed that about a third of society accepts it if the patient desires to not be a burden to family, to escape intolerable pain and suffering, or views life as meaningless due to terminal condition. Yet, about a third of the American population opposes physician-assisted suicide regardless of the reason behind its utilization (Emanuel, 2002).

A more recent study conducted by Emanuel, Onwuteake-Phillipsen,

Urwin, and Cohen (2016) replicated older findings. They demonstrated that support increased in 2005 to 75% but it decreased to about 65% in 2012 and has since remained steady. Overall, two thirds of American society support physician-assisted suicide.

Factors Predicting Attitude

It was important to identify the factors that contribute support and opposition of physician-assisted suicide to understand peoples' decision to support it. Even though about two thirds of the American population support physician-assisted suicide, the reasons for it and against it vary. Emanuel et al. (2016) identified that physician-assisted suicide is generally supported by those who are, male, not religious, and younger yet most participants were over the age of 65 and numbers were fairly even between males and female. Differing from Emanuel et al. (2016), Bulmer, Bohnke, and Lewis (2017) found that older people were more likely to support physician-assisted suicide. Also, those who identified as highly liberal, more extroverted, and less authoritarian were more likely to be in favor.

Additionally, Oregon and Washington's data reports indicated that most patients support physician-assisted suicide due to end of life concerns. Reasons for participating in physician-assisted suicide were due to loss of autonomy, loss of dignity, and decreased joy in life due to not being able to participate in activities (Washington State Department, 2016; Oregon's Death with Dignity, 2015). Additionally, people were more likely to support and participate when they

believe they are becoming a burden on others, losing independence and control, their pain is uncontrolled, or when they expected financial exhaustion (Washington State Department, 2016).

On the other hand, those who hold a strong religious affiliation, such as being Protestant or Catholic, and identified with conservative politics were most likely to oppose physician-assisted suicide (Bulmer et al., 2017). Also, those that opposed physician-assisted suicide did so because they feared that the practice will become routinized and be used by others beside the terminally ill (Emanuel et al., 2016). However, strict requirements restrict physicians from prescribing fatal medication to just anybody. Others felt that terminally ill patients would be pressured into it by insurances as a less expensive route. However, guidelines have been developed within the law to protect patients from being pressured, discriminated, or dropped by health and life insurances due to this practice (Assem. Bill 15, 2016).

Social Workers' Attitude

Essentially, any social worker may come across people who inquire about physician-assisted suicide, especially in those states where it has been legalized. Chances of this question enveloping are more than twice as likely for social workers who work in hospice due to its close relation to death and dying (Ogden & Young, 2008). Even though research on social workers and physician-assisted suicide is limited, the overall notion was that social workers, as a collective group accept physician-assisted suicide and support patients that express an interest in

it.

Ogden and Young (2008) confirmed that most Washingtonian social workers favored physician-assisted suicide and relevant methods for patients dying on their own terms. These social workers believed that patients should have the right to avoid unnecessary suffering and that denying them that right is immoral (Ogden & Young, 2008). It was also demonstrated that others believed that people have the constitutional right to privacy and to decide what is best for them. Importantly, these social workers believed that they should be involved with patients who consider physician-assisted suicide to protect their rights and assist in the decision-making process (Ogden & Young, 2008).

As mentioned previously, most patients who died due to physician-assisted suicide were under hospice care. Regarding Oregonian hospice social workers, most are supportive of the physician-assisted suicide laws enacted in their state (Miller, Harvath, Ganzini, Goy, Delorit, & Jackson, 2004). Also, most were supportive of patient's request for physician-assisted suicide. It was interesting to note that even though most social workers are supportive of physician-assisted suicide, some are little to not comfortable initiating the discussion with their patients (Miller et al., 2004). At some point, they may have wanted to, but they did not know how to approach it or if they should. Nonetheless, about one third of social workers would be comfortable being present when their patient administers the fatal dose, if requested to do so by the patient (Miller et al., 2004).

Social workers in relevant fields, like in medical settings, also work with terminally ill patients near the end of life and physician-assisted suicide may come up in conversation. Csikai (1999) reported that social workers' length of employment in the medical setting is related to their support for physician-assisted suicide. Those who invested more time in the field are more likely to support assisted suicide. Additionally, those social workers who felt strongly about physician-assisted suicide did not find it necessary for the patient to have to go through all other alternatives (Csikai, 1999). But, those who supported physician-assisted suicide did believe that the patient should be the one to request it and initiate the conversation. A shared consensus exists, both social workers who support and oppose physician-assisted suicide believe that that the family should not be permitted to make the request for the patient (Csikai, 1999). The purpose is to protect the patient from being pressured or abused and ensure that it is the patient's choice to move forward with physician-assisted suicide.

Social Work Practice

The legalization of physician-assisted suicide effects the practice of various disciplines of social work. Based on the data, it largely affects hospice social workers since they work directly with terminally ill patients near the end of life. However, physician-assisted suicide laws do not specify the role of social workers under this practice. Nonetheless, social workers are responsible for reviewing and understanding these laws and they should be reviewed regularly as updates occur (Hobart, 2001). The National Association of Social Workers

(NASW), however, does provide general standards for end of life care for social workers to follow.

The NASW Palliative and End of Life Care (2004) standards function as a guide for social workers working with the terminally ill or people at the end of life. These standards also function to assist family members, medical professionals, and the community. Following these standards, social workers gain competence in skills, practice, knowledge, and awareness of the diverse needs required to effectively assist and work in end of life situations (Palliative and End of Life Care, 2004).

End of life decisions are complicated but may be one of the most important decisions people make. These decisions are made directly by the person before the time of death or using an advance directive or a will. Nonetheless, these decisions are complicated considering the factors it involves such as ethics, religion, culture, emotions, legality, and policies (Palliative and End of Life Care, 2004).

Under physician-assisted suicide laws, social workers find themselves discussing this practice as well as other relevant options with terminally patients (Hobart, 2001). People at the end of life may have difficulty discussing these matters with their loved ones, therefore, social workers provide guidance in these situations through supportive counseling. It is important for social workers to understand, educate, and assist patients with advance directives to ensure their decisions will be respected (Hobart, 2001). In this regard, social workers

empower patients to make their own decisions and advocate self-determination, in an ethical manner.

Social workers aim to assist patients and families maneuver through such complex circumstances. They help in such situations due to their skills in interchangeable roles as clinicians, educators, researchers, advocates, and leaders (Palliative and End of Life Care, 2004). Their goal is to promote and maintain well-being, quality of life, as well as patient self-determination.

Because of the complexities involved at the end of life, it is best for social workers to remain unbiased and be aware of their own attitudes, beliefs, and concerns (Zilberfein & Hurwitz ,2003). The purpose of the social worker is to guide and assist the patient through their own decisions regarding their attitudes, beliefs, and concerns. Social workers may help terminal patients or those at the end of life manage their anxiety about death and dying and identify and manage emotions such as anger, grief, and guilt (Zilberfein & Hurwitz ,2003). Doing so aims to make the patient more comfortable and accepting, and, at the same time, return a sense of control, dignity, and self-determination to the patient.

Factors Challenging Support and Practice

Even though the NASW provided standards for end of life care, there are no specific protocols for how social workers should practice under physician-assisted suicide. However, social workers do follow the National Association of Social Workers' Code of Ethics, which may cause practical conflicts with this law. Physician-assisted suicide is technically a form of suicide and the Code of Ethics

urges social workers to intervene in these cases (Code of Ethics, 2008). Other conflicts relate to self-determination. It is open to individual interpretation to determine if a person's actions are a danger to self or others, if the social worker deems it so then they may intervene and limit one's right to self-determination (Code of Ethics, 2008).

Due to the inconclusiveness of the social workers' role ethical conflict occur. However, the lack of educational material and collegiate training may also pose as a challenge to social workers' attitude and practice under physician-assisted suicide (Berzoff, 2008). Although most social workers may have taken classes in death and dying, much less may have studied end of life issues. Such limited curriculum in turn leaves social workers feeling ill prepared and incompetent in effectively managing such circumstances (Berzoff, 2008).

Other issues arise when individual organizations hold policies that do not agree or chose to not participate in physician-assisted suicide practices (Miller, Hedlund, & Soule, 2006). However, it was important to bear in mind that the law allows physicians and organizations to decide for themselves whether they will or will not participate. Some nonparticipating organization have restricted communication between social workers and patients by not allowing physician-assisted suicide to be discussed at their site (Miller et al., 2006). As a result, social workers felt that they were unable to provide patients full services, connect them with diverse resources, and were limiting their right of self-determination (Miller et al., 2006).

Relevant to the latter, the social worker may feel conflicted in supporting or discussing physician-assisted suicide due to their own religion beliefs (Portenoy, Coyle, Kash, Brescia, Scanlon, O'Hare, Misbin, Holland, & Foley, 1997). Length of work experience also plays a factor. The more years of experience that a social worker has, the more comfortable and accepting with physician-assisted suicide they tend to be (Csikai, 1999). Therefore, newer social workers may not be as comfortable or supportive. If that is the case, and they cannot remain neutral, then those social workers can transfer their patient care to a different social worker, perhaps a more supportive one (Miller et al., 2006; Portenoy et al., 1997). The goal is to not abandon the patient in such a delicate stage in life. Additionally, some social workers may be hesitant to support and advocate physician-assisted suicide out of fear that the practice will be abused and that patients will be pressured into it (Csikai, 1999). Research identified that social workers who work in the medical field were more likely to support and participate under such laws than other colleagues.

It is important for the public as well as for helping professionals to understand physician-assisted suicide and its requirements. Equally important, helping professionals should be aware of society's general attitude toward physician-assisted suicide to develop appropriate policies. Awareness of social workers' attitudes and the factors that affect it, as well as, how their practice under this law is affected, helped one develop an understanding of its impact and implication. This data helped one discover what areas require more exploring.

This assisted in conducting interviews with hospice social workers to collect qualitative data. Such data can be used to develop an understanding and identification of how physician-assisted suicide and relevant factors affect Californian social worker's attitude and practice.

Theoretical Orientation

Since this study relates to physician-assisted suicide, relevant legislation, and social work practice, ethical conflicts may be inevitable. Therefore, the ethical theory of relativism was utilized for the orientation of this research. Essentially, ethical relativism states that there is no one absolute right or wrong but that morality is relative to what society's culture accepts as right and wrong (Velasquez, Andre, Shanks, & Meyer, 1992). It may be said that this thought process stands true regarding physician-assisted suicide. The theory holds the idea that each person has the right to make their own decision.

This theory of ethical relativism relates to this study because as a society of diverse cultures it would not be correct to apply an absolute judgement of action and restrict people's decision making. Terminally ill people should be able to maintain control of their actions and decisions at the end of life, whether it be to hastened death or to let death take its natural course. Social work aims to protect people's rights to have access to all end of life options and for people to make the decision to choose what they deem appropriate for themselves. This theory applies to the practice of social work since it aims to protect and advocate social justice, dignity, beneficence, and self-determination, while acknowledging,

understanding, and protecting individual and cultural diversity. Although physician-assisted suicide is a sensitive subject and a technical form of suicide, the circumstance is different. Reasoning for a terminally ill person to end their life at their terms is logical and justified due to their terminal prognosis and not irrational thought, risky behavior, or self-harm.

Potential Contributions to Micro and Macro Social Work Practice

The information gathered in this study is beneficial to both micro and macro social work practice. It may benefit micro practice by creating awareness of bias and ethical conflict between social workers' professional role and personal beliefs. Also, it functions as self-reflection on professional behavior and may solidify one's responsibility to adhere to the NASW Code of Ethics. This study educates on the importance of conserving empowerment and people's right to self-determination and right to social justice.

From a macro perspective, this study may motivate social workers to do their part in lobbying and advocating for people's right to die and promoting for increased accessibility to participating physicians across California. Also, this study may contribute to social workers' awareness and understanding of the state's legislation and policy regarding physician-assisted suicide. It promotes the need for developing practice standards or a guideline for social workers.

It is important to consider that physician-assisted suicide is a relatively new practice in some states of United States, especially in California, where it took effect in 2016. Therefore, social workers may not know how exactly to

manage or help a patient who makes the request to hasten their death. This leads to an ethical dilemma since social workers do not have a specific protocol to follow under this situation (Manetta & Wells, 2001). Nonetheless, it is necessary for social workers to keep up-to-date with their states legislation to ensure awareness of what options are available and the requirements for eligibility (Manetta & Wells, 2001). Not only is knowledge of state laws important for social workers but also to be knowledgeable in death and dying to better understand the situation and provide effective services.

Summary

Chapter one introduced this study's research focus on physician-assisted suicide, specifically California's End of Life Option, and effect on social workers. It identified and explained the reason for conducting this study under a post positivist perspective. The literature review provided an overview of physician-assisted suicide and its relation to social work practice. This chapter includes an explanation of the study's theoretical orientation and potential contributions to micro and macro social work practice.

CHAPTER TWO

ENGAGEMENT

Introduction

Chapter two identifies and describes this project's study site. It addresses the strategies for engaging with the site's gatekeepers. An explanation of the writer's self-preparation for engagement is provided. Additionally, anticipated diversity, ethical, and political issues are addressed as well as the role of technology in the engagement process.

Study Site

It was recognized that the number of social workers employed at hospice agencies are limited; therefore, this project attempted to involve various study sites to produce a reasonable number of participants. The utilized study sites were local hospice agencies in Southern California, specifically from the Coachella Valley. These hospice agencies provide end of life care for terminally ill patients and aim to provide a dignified, comfortable, and symptom managed dying process. Among many of their employed healthcare professionals are social workers, who focus on providing psychosocial and emotional support to patients and their loved ones. They help with care coordination, the financial aspects of hospice, and with connecting the patient and family with local community resources. Hospice social workers also assist patients understand their end of life options, identify their needs, and with fill out paperwork such as

advance directives. These local agencies service the Coachella Valley and some even service the High Desert.

Engagement Strategies for Gatekeepers

To gain access to hospice social workers this researcher engaged, via telephone call, with agency liaisons or office assistants to identify the appropriate director. Once the director was identified, the researcher called them to inform of the study's purpose and process. The director was also informed of the researcher's plans to recruit and interview their agency's social workers. Directors were emailed a permission letter explaining the research study process (See Appendix A). Without their approval, the researcher could not have met with and interviewed the agency's social workers. Once approval was attained, the researcher had flyers posted at the agency and the agency directors were asked to forward the flyer to their social workers via email (See Appendix B). The researcher then was contacted, via telephone and email, by hospice social workers who were willing to participate in the study. These social workers were given a brief verbal overview of the study's purpose then a date and time was set to meet for the interview.

Self-Preparation

The writer prepared for engagement by gaining an understanding of physician-assisted suicide, social workers' attitude towards it, California's End of Life Option Act and its effect on social workers practice. This knowledge was

gained through a comprehensive literature review.

The researcher kept in mind many possible issues that could arise. Even though California's End of Life Option Act legalized physician-assisted suicide throughout the state it does not obligate all organizations or physicians to participate. Also, there are strict requirements that patients need to meet to receive the lethal prescription. Additionally, because this practice is a type of suicide, it is a controversial topic and may be difficult to discuss. And most relevant to social work, California's law does not specify social workers' role under this law neither does the NASW, yet, it is relevant to social work, therefore, there may be confusion or hesitation about their role.

Also, by maintaining a narrative and self-reflective journal, the researcher became aware of her own perspective, bias, and attitude. This was beneficial since such awareness helped maintain an objective position throughout interviews with hospice social workers.

The researcher initiated engagement with the gatekeepers by providing them with a permission letter giving a brief overview of the study. The purpose and process of the study was verbally disclosed with participating social workers. A list of interview questions (See Appendix C) as well as a consent form (See Appendix D) was provided and explained to participants at the interview. Additionally, the researcher maintained awareness that focus may shift as data was collected and the study progressed.

Diversity Issues

Lack of diversity may have resulted since participants were selected exclusively from the Coachella Valley, which is a small agricultural region in southern California. In 2016, it was estimated that the Coachella Valley's nine towns had a cumulative population of 376,000 residents (Greater Palm Springs, 2016). Additionally, lack of diversity may have occurred since participants were specifically only hospice social workers, who are a fraction of the population in the area. As of 2013, only 13.3% of the Coachella Valley's population worked in the professional sector, which would have included social workers amongst various professionals (Annual Coachella Valley, 2014).

Even though Southern California as a collective is a diverse population, the Coachella Valley's population is largely minority based. As of 2012, about 51.4% of the Coachella Valley was Hispanic compared to 40.8% being White and 3.5% Asian/Pacific Islander (Annual Coachella Valley, 2014). Additionally, the Coachella Valley is considered a retirement community, therefore, participating social workers experience with death and dying may largely be based on elderly patients. In general, though, as of 2016, an estimated 25% of the Coachella Valley population was between the ages of 45-64 and about 20% was over the age of 65 (Greater Palm Springs, 2016).

This older and largely Hispanic population in the Coachella Valley may have affected diversity in social worker attitude and practice under California's End of Life Option act. Those of Hispanic background tend to be less supportive

of physician-assisted suicide and hold less positive attitudes towards it (Mouton, Espino, Esparza, & Miles, 2001). Even if afflicted with a terminal illness, this population is half as likely to consider this practice. This is in part due to the attitude and perception that suicide is wrong, however, it is more related to cultural beliefs than to religious affiliation (Mouton et al., 2001). Yet, religious affiliation is known to influence end of life decisions.

Therefore, lack of diversity in demographics as well as the expected small participant number voids results from being generalized outside of the Coachella Valley. However, to best analyze and understand this demography, the researcher took time to understand and acquaint with the participants. These participants were engaged with respect and awareness that each participant is their own individual person with their own values and beliefs.

Ethical Issues

To avoid ethical issues, prior to attaining data, approval was attained from the Human Subjects Review board. Also, approval was attained from each participating agency and individual. Participants were informed about the study and its purpose. They were given an informed consent form to sign prior to initiating interviews. Additionally, they were informed about the approximate length of time of the interview.

Due to physician-assisted suicide being a controversial topic and the novelty of California's End of Life Option Act, participants may have felt unprepared to discuss the topic or their attitude towards it. If participants felt

uncomfortable in completing the interview they were given the option to withdraw early from the study or to not answer questions they felt uncomfortable with. They were informed that they would not receive any consequences for doing so. Additionally, to ease anxiety or hesitance, participants' identity was protected and kept confidential by assigning an alias to them. A separate document was kept linking the identity with the alias. This document was kept in a private and secured location of which only the researcher had access to and was destroyed after interviews were transcribed.

Also, interview questions did not ask for identifiers such as participant name, name of agency, or city location of agency. Participants were ensured that their response would be utilized solely for research analysis purposes and would be free of the researcher's judgement or bias. Data was collected via recorder then transcribed into journals. Recorded data was destroyed as soon as they were not needed.

Political Issues

Again, due to the controversy of the subject and novelty of California's law, the researcher was aware that issues could rise from the lack of policies and practice standards involving social workers. Some agencies the researcher attempted to gain approval from rejected participation. They felt unprepared to be involved or were hesitant to participate due to fear of repercussion from non-supports, who are financial contributors or clients. Likewise, they may have feared repercussion from supporters if the organization decided to not participate

under the newly enacted act. Nonetheless, gatekeepers were reminded that their organization would remain anonymous under mutual consent and confidentiality.

Role of Technology in Engagement

Most engagement and data collection were completed from face to face interviews with participants. However, initial contact was made through telephone calls and follow up or reminders were made through e-mail. The use of technology was beneficial since multiple study sites were used, and it would have been difficult to rely solely on face to face interaction.

Summary

Chapter two addressed the engagement process of this study. It identified the study site as local hospice agencies in the Coachella Valley, in Southern California. Strategies for engaging with social work department directors were provided to gain access to participants. How the writer plans to prepare for the engagement and use technology was explained as well as possible diversity, ethical, and political issues.

CHAPTER THREE

IMPLEMENTATION

Introduction

Chapter three covers the participants of the study and explains the reasoning for their selection. This chapter addresses the data gathering method and the phases of data collection. It describes how data is recorded and analyzed. The study's termination and follow up process is explained as well as the method of communicating findings and the dissemination plan.

Study Participants

The study participants in this study were hospice social workers because their practice is relevant to physician-assisted suicide. Hospice agencies in the Coachella Valley have between one to five social workers working for them. Considering this, the study aimed to attain at least 10 participants, however, only 8 were interviewed. Participants were both female and male social workers over the age of 18 and of diverse ethnicity, cultures, and background.

Hospice social workers assist patients and family with the death and dying process, may connect them to additional community resources, and offer counseling to improve and maintain emotional, psychological, social, and physical well-being. These social workers hold at least a Master of Social Work (MSW) degree but some were licensed clinical social workers (LCSW), too. Also, they work with people of all ages, ethnicity, religious affiliation, stages of life, and

medical, physical, and social needs. Considering what their practice entails and that they work with patients who are terminally ill and/or in the dying process, they are likely to encounter situations and questions relevant to the End of Life Option Act in their practice.

Selection of Participants

This study was conducted under the post positivist perspective and the selection of participants was based on purposive sampling. These participants were selected through a homogeneous sampling of social workers in the death and dying field. Specifically, they were hospice social workers. The purpose was to develop an in-depth study of physician-assisted suicide and social work practice. Participants were selected strictly from local hospice agencies in the Coachella Valley. This produced detailed findings that enhanced understanding of California's End of Life Option and its effect on hospice social workers' practice. Also, it helped identify the factors affecting their attitude towards physician-assisted suicide.

Participants were recruited by engaging gatekeepers such as hospice liaisons and agency office assistants to reach their directors. Liaisons were approached directly to inquire how many social workers the agency had as well as who the director or person to seek approval from was. The researcher then contacted that person via telephone call and/or email to inform them of the study's purpose. Then permission letters, giving an overview of the study's process, were emailed to them to review for approval.

When agency approval was attained, as well as approval from the Human Subjects Review Board, the researcher posted recruitment flyers at the agency's premises and asked the directors to forward the flyer to their social workers via e-mail. The flyer gave a brief explanation of the study, who was conducting the study, that \$5 Starbucks gift cards were available to participants, and how they could contact the researcher to participate. Social workers interested in participating contacted the researcher. Then, a date and time was set for the interview.

Data Gathering

Qualitative data was gathered through individual interviews with hospice social workers. These interviews were conducted at their agency location to maintain the naturalistic setting and nature of the research. Interviews were recorded via recorder and journals were kept for interview transcripts. Keeping a journal to review transcripts allowed the investigator to self-reflect on the interview process. It created awareness of effective and ineffective interview questions as well as to what questions were missing to gain complete and comprehensive data.

The initial interviews were structured but it was understood that the process could change as the study progressed. Participants were asked explorative, case, and experience verification questions to understand their attitude towards physician-assisted suicide and their practice under California's End of Life Option Act.

They were questioned about their knowledge of physician-assisted suicide and of California's End of Life act. Their understanding of their role under this law was examined as well as their attitude towards it. The interview explored how or if a social worker's religious affiliation and values affected their professional role. Also, if their professional experience in death and dying, professional ethics and values, and comfort in working with the terminally ill affected their sense of preparedness to practice under the End of Life Option Act.

Phases of Data Collection

Initially, the writer established rapport with agency directors to inform them of the project seeking agency approval to participate in the study. A recruitment flyer was used to attain hospice social workers' interest in participating in the study. Interviews were conducted with participating social workers and interviews were audio recorded, but only if the participant agreed to it. If the participant did not want to be audio recorded during the interview, written notes were taken.

To collect data for this study, a list of structured interview questions was developed to aid the interview process and provide participants with a similar experience. However, the researcher was aware that as the study progressed that the process may change to explore different aspects of physician-assisted suicide and the End of Life Option Act. The questions used in the interview were descriptive and structural. The questions functioned to explore social workers' attitudes, opinions, and understanding and do identify patterns in the collected data. This served to develop identification and explanation of what factors

affected these social workers attitude towards physician-assisted suicide and how their practice is affected by the End of Life Option Act.

To ensure a smooth interview process, the researcher engaged with the participants prior to asking interview questions. This was accomplished by asking them questions such as what it is like to be a hospice social worker and what a typical work day consisted of. Once the participant seemed more comfortable, the researcher shifted focus towards the physician-assisted suicide and the End of Life Option Act. Therefore, the researcher began to ask questions from the interview question list. The questions became more specific to maintain focus of the study. The researcher checked with the participant to confirm that their responses were accurately understood. The researcher did this to confirm that the collected data accurately represents the participants' attitude and perspective. The researcher asked for feedback from the participant and ensured that any questions or concerns have been answered.

After the interview, the researcher used the audio recorded interview to transcribe the data into a written narrative. Journals were kept for record keeping, self-reflection, and to aid ensuing interviews. This allowed the researcher to reflect on the interview process, the questions used, and the data collected as well as to identify if the questions collected the needed and comprehensive data. Participants were informed that if additional questions came up they would be contacted via email or telephone. Also, participants could contact the researcher the same way. Participants were then debriefed participation terminated.

Data Recording

Participants were given a consent form to sign and were informed about confidentiality prior to initiating interviews. Interviews were audio recorded to ensure that accurate data was collected. If participants wished to not be recorded, handwritten notes were done during the interview.

To maintain confidentiality, participants were given an alias before interviews began. A separate document was kept linking the identity with the alias. This document was kept in a private and secured location of which only the researcher had access to. Additionally, interview questions did not ask for identifiers such as participant name, hospice agency name, or agency location. The recording device was kept in a secured location that only the researcher had access to. Interviews were transcribed soon after interviews are concluded. After ensuring that transcriptions are accurate, the recorded data was destroyed. Journals were kept in a secured location that only the researcher had access to.

Data Analysis

To analyze the data, a bottom up approach was used following its open coding, axial coding, selective coding, and conditional matrix stages. In the open coding stage, the interviews were broken down to narratives and analyzed. This organized information allowed development of concepts and meanings related to the social workers' role in the End of Life Option Act.

Using axial coding, connections were made between the concepts developed from the interview analysis. This led to an understanding and

explanation of social workers' attitudes and their thought processes towards physician-assisted suicide.

Using selective coding, a theory started to develop. The purpose was to give an overall explanation of the data gathered from interviews as well as from the literature review. The theory described and explained how California's End of Life Option Act affects social workers' role, attitude, and practice.

Finally, the conditional matrix stage was used to suggest and explain how the theory and findings relate to various micro and macro aspects of social work. The findings are anticipated to contribute to both micro and macro social work practice.

Termination and Follow Up

After interviewing the participants and gathering the needed data, termination followed by answering any questions or concerns the participant had. Participants were then debriefed (See Appendix E). Participants and the gatekeepers were thanked for their time and participation. Participants and gatekeepers were also given contact information in case of additional questions. The researcher provided the agency and participants with information on when and how to access the completed research report.

Communication of Findings and Dissemination Plan

The findings of this study were communicated in the form of a comprehensive research project and reported to the Social Work department at

California State University, San Bernardino. Findings were also made accessible to the participants.

Summary

Chapter three presented the study participants and explained why and how they were selected for research. How data would be gathered, including the phases of collection, recorded and analyzed was addressed. The termination process and follow up was described as well as how findings will be communicated and disseminated.

CHAPTER FOUR

EVALUATION

Introduction

Chapter four covers the evaluation of data collected from interviewing participants in the study site. This section provides a data analysis introducing participant demographics and general information. The cross-participant analysis presents developed themes and comparisons in participant responses. The data interpretation section gives meaning to the responses and validates the findings through supportive evidence found in other studies. This chapter also discusses the implications for micro and macro practice based on its findings.

Data Analysis

In this study, eight participants were recruited from the Coachella Valley, in Southern California. All participants were hospice social workers, and 75% of the participants were female and 25% were male. All participants had worked as social workers anywhere from four to 45 years but about 60% of the participants had an average 5 years work experience. Three of the participants were new to the field of hospice with less than 1 year working in hospice, however, the rest had worked in hospice for an average of 4 years. Regardless of the participants experience in hospice social work, all participants were knowledgeable of what their role as a hospice social worker involved, though some responses were more detailed than others. One participant informed that as a hospice social

worker, her responsibilities were to “assess for psychosocial needs, conduct assessments, and provided support as needed.” Another stated her job involved, conducting biopsychosocial assessments, providing counseling for family and the patient. Providing bereavement support to family. Educating family and patients on the role of hospice. Advocating on behalf the patient and family to ensure that their needs are being met, and their final wishes are granted. (Participant 7, October 2017)

Cross Participant Analysis

Regardless of the participants’ experience as social workers or of working in the field of hospice, all participants stated feeling prepared to assist patients and/or families in end of life decision making. For example, when asked about this, one of the participants stated, “for the most part yes, however, each family is different and unique in their needs and beliefs.” (Participant 7, October 2017) Another participant stated, “I do feel prepared although I certainly do not think that I have all the answers but do have a supervisor and peers I can go to talk it over with.” (Participant 1, June 2017) Also, in interviewing the participants it was found that all were comfortable with discussing different end of life options with patients and/or their families.

The previous questions led the way for the following questions, which were the focus of this research. When participants were asked about their attitude towards physician-assisted suicide, all participants had a positive attitude towards it and were supportive of its practice due to individual’s right to self-

determination and well-informed decision making. This was evidenced by responses such as “I am very pro self-determination for the client. At the end of everything this is their life and their choices... But for me, I think it’s a good thing, it’s a great thing for people to have a choice to do that when they’re that terminally ill.” (Participant 3, July 2017) Supportive attitude for physician-assisted suicide was also due to believing people should be allowed to escape suffering and a painful death as was understood by responses such as this participant’s, “we assist pets and other non-human beings when they are not doing well so I don’t understand why we wouldn’t do the same for a human being who is experiencing pain and suffering.” (Participant 1, June 2017)

In exploring what factors influenced participant’s attitude on physician - suicide, it was found that all participants believed some factors influenced their support for physician-assisted suicide. For example, all participants believed that their professional experience influenced their support through statements such as, “seeing what patients go thru at the end of life and knowing that there are other options that would give them more of a say on what goes on and how they pass” and “well, working with people who are near death or have a terminal illness has impacted by attitude about assisted suicide, it’s a large part of why I support it. If I didn’t work in this environment I may not understand its importance.” (Participant 8, November 2017)

When asked how their profession’s ethics and values influenced their attitude on physician-assisted suicide, all participants reported it them to be

aligned with their support for physician-assisted suicide. For example, one participant stated, "I feel the values and ethical responsibility as a social worker fall in line with this in terms of empowering the client to take control and allowing self-determination." (Participant 7, October 2017) Another participant's response was similar when they said, "Yes, especially in hospice because both aim to respect the wishes of patients at end of life and if their sane of mind then they should have the right to decide how to end their life." (Participant 5, July 2017)

In terms of personal values, all participants believed they influenced and supported their attitude towards physician-assisted suicide. Participants demonstrated this in stating, "I would not want to see anyone in pain or suffering. I do not believe in keeping people alive to keep them alive if they don't have any opportunity to improve or feel that their life will get any better" and "I hold strong value on dignity and compassion, so I believe that no one should be forced to suffer in their dying process." (Participant 7, October 2017)

All but one participant believed their personal experiences had any influence on their attitude towards physician-assisted suicide. The common theme for these participants was their experience of seeing or knowing how people suffered and changed in the dying process. This was evidenced in responses such as "I've seen people suffer at the end of life and I don't think it is right. We should be able to help people go easily, with dignity, and without pain." The participant who believed their personal influence had no influence on their attitude stated it to be so because "I have always believed that no one should be

forced to suffer.” (Participant 7, October 2017) When asked about religion as a factor, all participants indicated that it had no influence on their attitude towards physician-assisted suicide. For example, one participant stated; “it probably should but no” while another said there was “absolutely no influence.” The interviews also found that most participants either did not receive end of life training and did little to no research on physician-assisted suicide and they had no influence on their attitude towards it.

In exploring the effect of California’s End of Life Option Act on hospice social work practice, only one of the eight participants believed that this law would not affect their practice. This participant believed it wouldn’t affect her practice because “I will continue to do the same I always have- support, educate, and advocate.” (Participant 7, October 2017) However, everyone else believed it would affect their practice as was evidenced by responses such as “I believe it gives people another option and me another resource to share with them and having the knowledge of these resources is critical” (Participant 1, June 2017) and “it does because in a sense it is our competitor, but it allows us as social workers to offer patients another option at their end of life.” (Participant 4, July 2017)

This question also shed light on the difficulties that the End of Life Option Act can create. For example, one participant stated,

and it gets tricky because people have different feelings and patients feel that they will not be supported, and they can become frustrated or

depressed. I feel this impacts us because if they feel that information is blocked then what are they going to do themselves about it? (Participant 3, July 2017)

Also, resources and accessibility are limited in relation to the End of Life Option Act as evidenced by a participant stating, "I believe it could enhance our work, if it was practical and really applied, but resources are scarce, so it makes it difficult out here to use," (Participant 5, July 2017) Similarly, another participant stated, "it gives us another option to educate and help patients access but out here there isn't many or really any doctors willing to write the prescription." (Participant 8, November 2017)

One participant did not feel prepared to discuss the End of Life Option Act with hospice clients. This participant stated that he would feel prepared to discuss this option with clients, "...once I have more information and have had the opportunity to read on it and digest and understand the information. And have been able to ask the question I have on it." (Participant 1, June 2017) On the other hand, another participant stated, "now I do, originally not so much since we didn't have so much information to give to the patient. It is easier now." (Participant 3, July 2017) All other research participants felt prepared to discuss this option and it can be implied that their sense of preparedness is based on the information they have, their understanding, and their experience. As stated by one participant, "the longer I have been in the hospice field the more comfortable I have become in addressing any needs at the end of life." (Participant 6, July

2017)

Like the last question, when participants were asked if they knew what to do when someone asked or requested to participate in California's End of Life Option, all but one participant stated to know how to handle that situation. This sole participant stated, "not sure but I will ask," (Participant 1, June 2017) however, this is the same participant who was new to the hospice field and had limited knowledge of California's End of Life Option. All other participants disclosed knowing how to handle a request for the End of Life Option. For example, one participant stated, "I'll educate them and their family about what it is and how it works, I help them connect with a doctor or another resource that has more information and connections." (Participant 8, November 2017) Another informed that, "I would discuss this with them and provide support but ultimately, they would need to begin a discussion with their physician." (Participant 7, October 2017)

Data Interpretation

The study found that all participants were supportive of physician-assisted suicide. Unfortunately, there is not much research on social work and physician-assisted suicide despite their practice with the terminal ill, like those in the field of hospice. Most studies involving social workers are based from Oregon, and these studies demonstrate that hospice social workers viewed maintenance of dignity in the dying process as important in supporting physician-assisted suicide (Ganzini, Harvath, Jackson, Goy, Miller, & Delroit, 2002). Another study

demonstrates that a large part of social workers supports physician-assisted suicide. The study found that social workers tended to be more supportive as they accumulated experience in the field of social work, especially if they work with the terminally ill (Erlbaum-Zur, 2006).

This study also found that personal and professional experience as well as personal and professional values were interrelated and aligned with the participants' attitude towards physician-assisted suicide. The dominant reason for the support amongst participants was valuing the right of self-determination and to reduce pain and suffering in the dying process. This finding is consistent with Csikai's (2000) finding that hospital social workers viewed self-determination in end of life matters as most important. This also aligns with personal values as is evident in Blevins, Preston, and Werth's (2005) study finding that people support and would consider physician-assisted suicide if they were to be terminally ill and experienced decreased sense of control and quality of life and increased suffering. Also, participants support physician-assisted suicide because as social workers they want to respect and support their client's wishes and ensure their end of life decisions. This is consistent with a study demonstrating that social workers are supportive of their patient's choice to promote the patient's sense of control, independence, and quality of life when they are ready to die (Ganzini et al., 2002).

Religion was not an influential factor for any of these participants. Religious beliefs or affiliation did not impact their attitude towards physician-

assisted suicide. This finding is inconsistent with Bulmer et al.'s (2017) finding which indicated that religious affiliation would cause opposition of physician-assisted suicide and such practices. Interestingly, one participant stated that her religion "probably should but it doesn't" (Participant 8, November 2017) affect her support towards physician-assisted suicide. The latter may be due to social workers' ability to separate their personal beliefs and professional practice and value respect for individual's self-determination.

This study found that most social workers believed that the California End of Life Option Act would affect their practice. Some believe the effect is simple since it just provides them with a new option to educate clients on when requested. However, some of the participants believe that some difficulties may arise. This is due to how new the law is and how little resources are available to clients, especially, in smaller towns such as those in the Coachella Valley. Like a participant disclosed, they can provide the patient with information but struggle to connect them with resources and there's only one doctor willing to participate in the whole Coachella Valley. Unfortunately, because this law is so recent there currently is little information on its implementation and relation to social work practice. However, considering that most recipients that died under similar laws were active hospice care patients (Oregon's death with dignity, 2015; Washington State Department, 2016), it is implied that hospice social workers will encounter this in their practice. Hospice social workers assist patients and their family in end of life planning and case managing patient's requests, therefore, they should

expect and be prepared to answer questions related to this law.

Despite the challenges that may come up in these social workers' practice, most believed that they are prepared to discuss California's End of Life Option Act, even if they have not received formal training on this specific law, due to previous training and work experience. This is attributed to the guidance that social workers receive on end of life practice through the NASW and maintenance of self-determination (Manetta, 2001). Also, as participants stated, when California's End of Life Option Act passed their agencies provided in-services to educate their staff about the law, how to assist, and connect patients with appropriate resources. Additionally, hospice professionals are prepared to discuss such a topic due to their openness to communication, their understanding of the dying process, and readiness to maintain a helping relationship with patients, even when disagreements come up (Arnold, Artin, Person, and Griffith, 2004).

Implications of Findings for Micro and Macro Practice

Considering the limited research on the impact of physician assisted-suicide and similar legislation on social work practice, these findings highlight the need for research to be conducted. This is important since social workers are involved and expected to handle such requests as part of the patient's treatment team. Especially in California where the End of Life Option Act is new, it would be beneficial to study how this law affects social work practice and what could be done to enhance their involvement and service delivery. This would particularly

be crucial in the field of hospice since most End of Life Option participants are anticipated to be hospice patients.

These findings imply that social workers are supportive of physician-assisted suicide and feel prepared to discuss this option with terminally ill patients and their families. Though this finding demonstrates social workers' ability to adapt to change utilizing previous similar experiences in new situations, a standardized protocol could be beneficial. Yet one has not been established for social workers. It is important for social workers to have a standardized protocol to follow to ensure safety and best service delivery. Additionally, resources are limited, and this can cause difficulties in service delivery. Accessibility for this type of resource needs to be increased. Therefore, it is crucial for policy makers and administrators to advocate and push for increased community resources.

Summary

This chapter presented an evaluation of data collected from interviewing participants to attain their attitude on physician-assisted suicide and their perception of how California's End of Life Option Act affects their practice. A data analysis introduced general participant information such as sex, length of time working in social work, and length of time working in the field of hospice. The cross-participant analysis presented themes developed based on participants' responses and compared participant responses. The data interpretation gave meaning to participant responses and presented support for the study's findings. This chapter also discussed the implications for micro and macro practice.

CHAPTER FIVE

TERMINATION AND FOLLOW UP

Introduction

Chapter five presents the termination of the study as well as the communication of findings to the study site and the participants. This chapter explains how an ongoing relationship with the study site and participants will be maintained and the benefit of doing so. This chapter also covers the dissemination plan.

Termination of Study

Termination of the study was initiated when the researcher informed the hospice agency directors that the anticipated completion and availability of the study would be after July 2018. Termination was completed with each participant at the time of their interview when they were given the debriefing statement, which also informed them that this study would be completed and available after July 2018. After the study is completed, the researcher will email each director to thank them and the participants for being part of this study and terminate the study's activity.

Communicating Findings to the Study Site and Study Participants

The study's findings will be communicated to the study site, and, consequently, the participants, through the publication of the project at California

State University, San Bernardino's Pfau Library. The thank you email that the researcher will send to the hospice agency directors will provide the ScholarWorks link (<http://scholarworks.lib.csusb.edu>) that can be used to access the study online. That same email will inform the director and participants of the study's date availability, too. In case the study sites are unable to access the published study, the researcher will make herself available to obtain a copy and provide it to them. Accessibility of the published study is beneficial for the study site and participants to review and identify the contributions that their input made toward micro and macro social work practice. Additionally, this study communicates the need for further research on how California's End of Life Option Act affects social work practice and how to better address their role under such legislation. This study also indicates that, despite the lack of research or direct address in legislation, social workers are flexible and adaptable to change.

Ongoing Relationship with Study Site and Participants

A relationship will be maintained with the study site directors and the participants in case they have any questions regarding the study or its findings in the future. The researcher will make herself available via email to answer questions and assist in accessing the published study via the university's ScholarWorks website (<http://scholarworks.lib.csusb.edu>). Maintaining an ongoing relationship with the study site and participants will allow for future discussion and communication to occur and for the researcher to explore if the findings were helpful or significant to them and their practice. Those participants

that were new to the field of hospice, felt unprepared to discuss California's End of Life Option Act, or were unsure on how to handle such request may find comfort in knowing that currently the law does not address their practice directly. However, because the participants agree that this law does affect their practice this study may function to start communication between them and their directors or even administrators and policy makers.

Dissemination Plan

The study will be published on to the ScholarWorks (<http://scholarworks.lib.csusb.edu>) website in July 2018. Study site directors and participants will be reminded of this date and how to access the published study via email. This researcher will make herself available to directors and participants via email in case they are unable to access the study. If that is the case, this researcher will either assist them in accessing the study online or will attain and provide them with a copy of the study. Study site and participants will be reminded that they are welcome to review the study findings and contact the researcher with any questions that they may have.

Summary

The last chapter of this study, explained the termination process of the study as well as how findings would be communicated to the study site and the participants. This chapter explained why an ongoing relationship with the study site and participants is beneficial and how it would be maintained. Lastly, this

chapter discussed the dissemination plan and informed of how the publication of this study could be accessed.

APPENDIX A

PERMISSION LETTER



College of Social and Behavioral Sciences
School of Social Work

To whom it may concern:

My name is Veronica Lorraine Fausto Melchor and I am a Master of Social Work student at California State University, San Bernardino. I am currently preparing for my Master's research study. My research aims to identify the factors that affect social workers' attitude towards physician assisted suicide and how the End of Life Option affects social work practice.

I am seeking your agency's approval to participate in my study and to allow me to interview your agency's social worker(s).

I will interview social workers individually. I estimate interviews to last 30-45 minutes. In case additional questions develop after the interview, I will follow up via email or telephone. Interviews will be held at a time and place that is convenient to the social worker. Prior to the interview, I will provide interview questions and a consent form to each social worker to review. The identity of your agency and social worker(s) will remain confidential.

Upon completion of the study, I will provide the agency with a copy of the full research report.

If you wish to grant me approval, I will need an approval letter on your agency's letter head. Following this letter, I have provided an outline for the approval letter.

I will submit my research proposal to CSUSB'S Institutional Review Board for approval on March 19, 2017. After attaining approval, I will be able to recruit individual participants. I plan to use an informational flyer to gain their interest and willingness to participate. I also ask for permission to post a flyer at your agency and for you to forward the flyer to your social worker(s) via email.

Thank you for your time and consideration,

Veronica Lorraine Fausto Melchor
Faustomv@coyote.csusb.edu
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Human Subjects Committee
School of Social Work
CSUSB
5500 University Parkway
San Bernardino, CA 92407

This is to confirm that Veronica Lorraine Fausto Melchor has permission to carry out her research project on social workers' attitude towards physician assisted suicide and the effect of the End of Life Option Act on social work practice at (name of agency). She will be gathering data from our agency's social workers by interviewing them. The data will be gathered between April 01, 2017, to June 30, 2018.

(Agency Director)

5500 UNIVERSITY PARKWAY, SAN BERNARDINO, CA 92407-2393

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APPENDIX B
RECRUITMENT FLYER

PARTICIPANTS NEEDED

You are invited to participate in a study identifying the factors that affect social workers' attitude towards physician assisted suicide and the effects of the End of Life Option Act on social work practice



conducted by Veronica Lorraine Fausto Melchor, MSW student from the School of Social Work, California State University, San Bernardino.

The study involves individual interviews estimated to last 30-45 minutes.

\$5 Starbucks gift cards are available.

If you are at least 18 years old and are a hospice social worker and would like more information about participating, contact:
Veronica L. Fausto Melchor at (760) 625-5689 or
Faustomv@coyote.csusb.edu

5500 UNIVERSITY PARKWAY, SAN BERNARDINO, CA 92407-2393

APPENDIX C

INTERVIEW QUESTIONS

1. How long have you been practicing social work?
3. How long have you been working in this (hospice) field?
4. What does your job involve?
5. Do you feel prepared to assist patients and/or families in end of life decision making?
6. How comfortable do you feel discussing different end of life options with patients or their families?
7. What is your attitude towards physician-assisted suicide?
8. How have these factors influenced your attitude towards physician-assisted suicide-
 - professional experience?
 - professional ethics and values?
 - your community and its demographics?
 - personal experience?
 - personal values?
 - religion?
 - end of life training?
 - research?
 - agency?
 - other?

9. Were you aware that physician-assisted suicide (dying) was legalized under California's End of Life Option Act?
10. What do you know about this law?
11. Do you believe it affects your practice in social work?
12. Do you feel prepared to discuss the end of life option with patients or their families? Why?
13. Do you know what to do if someone requests the End of Life Option? How would you handle it?
14. Have you attended any educational events or trainings on this law to inform you what it entails or how to handle a request for it?
15. Do you know of any protocols or guidelines for social work practice regarding End of Life Option Act?
16. Does your agency have a practice protocol for patients requesting it?
17. Do you think social workers should discuss the end of life option act with terminally ill patients?

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APPENDIX D

CONSENT FORM

California State University, San Bernardino
Social Work Institutional Review Board Sub-Committee
APPROVED 4/1/2019 VOID AFTER 4/1/2020
IRB SWIRB CHAIR Janet Chang



College of Social and Behavioral Sciences
School of Social Work

INFORMED CONSENT

The study in which you are asked to participate in is designed to identify factors that affect hospice social workers' attitude on physician assisted suicide and how the End of Life Option Act effects social work practice. The study is being conducted by MSW student Veronica Lorraine Fausto Melchor, under the supervision of Dr. Janet Chang, Professor in the School of Social Work, California State University, San Bernardino. The research has been approved by the Institutional Review Board Social Work Sub-committee of California State University, San Bernardino.

PURPOSE: This study aims to identify factors effecting social workers' attitude towards physician assisted suicide and the effect of the End of Life Option Act on social work practice.

DESCRIPTION: Participants will be individually interviewed at a time and place of their convenience. Questions will be asked regarding the factors affecting their attitude towards physician assisted suicide and how the End of Life Option Act has or may affect social work practice.

PARTICIPATION: Your participation is entirely voluntary. You can refuse to participate or terminate your participation at any time, as well as not answer an interview question, without any consequences.

CONFIDENTIALITY: Your identity will remain confidential using an alias, and data will be reported using an alias. Audio recorded data will be destroyed after accurately transcribed.

DURATION: Interviews are estimated to last about 30-45 minutes.

RISKS: There are no foreseeable risks to the participants. But some of the interview questions may be sensitive and pose some discomfort. In order to address such discomforts, a debriefing statement will be given to the participants.

BENEFITS: There may be no direct benefit to the participants, but the data gained may be of value and contribute to the social work discipline.

CONTACT: If you have any questions about this study, feel free to contact Veronica Lorraine Fausto Melchor at (760) 625- 5689 (faustomy@csusb.edu) or Dr. Janet Chang at (909) 537-5184 (jchang@csusb.edu).

RESULT: Results of the study will be available at the ScholarWorks
(<http://scholarworks.lib.csusb.edu>) at the Pfau Library, California State University, San Bernardino
after July 2018.

This is to certify that I read the above and I am 18 years or older.

Place an X mark here

Date

I agree to be tape recorded: _____ Yes _____ No

909.537.5001 909.537.7029

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The California State University - Bakersfield - Channel Islands - Chico - Dominguez Hills - East Bay - Fresno - Fullerton - Humboldt - Long
Beach - Los Angeles Maritime

Academy - Monterey Bay - Northridge - Pomona - Sacramento - San Bernardino - San Diego - San Francisco - San Jose - San Luis Obispo - San Marcos
Sonoma - Stanislaus

APPENDIX E

DEBRIEFING STATEMENT



College of Social and Behavioral Sciences
School of Social Work

DEBRIEFING STATEMENT:
Study of Physician Assisted Suicide and the End of Life Option Act

The study you have completed is designed to explore hospice social workers' attitude on physician assisted suicide and how the End of Life Option Act affects this social work practice. Past research indicates that for the most part social workers are supportive of physician assisted suicide, however, there are factors that affect social workers' attitude. It is a sensitive topic that does not have clear guidelines for social workers. The End of Life Option Act also does not have clear guidelines for social workers in California. Considering how new this law is, how exactly this will affect social work practice in California has not been comprehensively studied. Specifically, the purpose of this study is to identify hospice social workers' attitude towards physician assisted suicide and what factors affect it, as well as, how the End of Life Option Act affects this social work practice.

Given the sensitive nature of this topic, some participants may experience some discomfort or distress after discussing this issue. In case assistance or counseling is needed, reach out to the Indio Mental Health Clinic at (760) 863- 8455, Eisenhower Behavioral Health at (760) 837-8767, or any other local mental health agency.

Thank you for taking the time to participate in this study. If you have any concerns or questions regarding the study, please, contact Veronica Lorraine Fausto Melcher (lfausto@csusb.edu) or Dr. Janet Chung at (909) 537-5184 (jchung@sb.edu). A copy of the study report will be available at your request after July 2018 or at the ScholarWorks (<http://scholarworks.lib.csusb.edu>) at the Pfim Library, California State University, San Bernardino.

909.537.5501 - 909.537.7029

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APPENDIX F

INSTITUTIONAL REVIEW BOARD APPROVAL

CALIFORNIA STATE UNIVERSITY, SAN BERNARDINO
SCHOOL OF SOCIAL WORK
Institutional Review Board Sub-Committee

Researcher(s): Veronica Lorraine Fausto Melchor

Proposal Title: Hospice social workers' attitude on physician assisted suicide and practice under the End of Life Option Act

SW1744

Your proposal has been reviewed by the School of Social Work Sub-Committee of the Institutional Review Board. The decisions and advice of those faculty are given below.

.....
Proposal is:

☒ approved

☐ to be resubmitted with revisions listed below

☐ to be forwarded to the campus IRB for review

Revisions that must be made before proposal can be approved:

☐ faculty signature missing

☐ missing informed consent ☒ debriefing statement

☐ revisions needed in informed consent ☐ debriefing

☐ data collection instruments missing

☐ agency approval letter missing

☐ CITI missing

☐ revisions in design needed (specified below)



Committee Chair Signature

4/20/2017

Date

Distribution: White-Coordinator; Yellow-Supervisor; Pink-Student

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